

Reporting on psychological wellbeing of older adults with chronic aphasia in the context of unaffected peers

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Abstract

Purpose: It is important that professionals working with individuals with acquired neurogenic communication disorders consider their clients' psychological wellbeing. Much is known about the significant emotional, social and psychological consequences of aphasia after stroke, however little is known about individuals' psychological wellbeing. This paper reports the psychological wellbeing of community-dwelling older adults with chronic aphasia in the context of their unaffected peers.

Method: Thirty participants affected by aphasia and 75 unaffected participants completed the 24-item measure *How I Feel About Myself* drawn originally from Ryff (1989) and the *Geriatric Depression Scale* (Sheikh & Yesavage, 1986).

Results: Individuals with aphasia after stroke had statistically similar range and average psychological wellbeing as the unaffected population, with the exception of lower environmental mastery (independence) and lower mood. Furthermore, a substantial number of individuals (affected and unaffected) reported lower than average psychological wellbeing.

Conclusions: Many persons with chronic aphasia need support to manage the demands and responsibilities of their everyday lives and raise their mood. Clinicians need to be aware of this possibility and formally assess all persons with aphasia, as well as explore the potential impact of physical limitations. Identifying low well-being in older adults is important for all professionals working with the ageing population. The implications for speech and language therapy and for multi-disciplinary research and cross-sector joint working (health, social and community services) are discussed.

Introduction

In the field of healthcare and health interventions, there is increasing interest in the use of wellbeing as a measure of quality of life to reflect on the effectiveness of client outcomes and service provision. Quality of life is generally understood as the umbrella concept, encompassing both health-related quality of life (quality of life pertaining to health conditions or quality of life in health domains only) and wellbeing. The rise of wellbeing in quality of life has been largely due to the increased recognition of the patient's perceptions in healthcare, the increasing use of qualitative research methodologies typically employed to investigate this field, and the ongoing development of wellbeing measures. Subjective wellbeing is the most common term used, and includes the constructs of life satisfaction, positive affect, and negative affect. The subject of this paper, *psychological* wellbeing is typically comprised of mental health, cognitive judgements of overall life satisfaction, and positive and negative emotions (Birren et al., 1991). As such, it is a combination of subjective wellbeing and mental health. Other concepts sometimes considered are coping skills, self-esteem and adjustment to illness. According to Carol Ryff, a lifelong researcher in the field, psychological wellbeing also includes positive relations with others, autonomy, purpose in life, and personal growth (1989).

The existing research on the psychological, social and emotional sequelae of aphasia and stroke can inform our expectations of affected individuals' psychological wellbeing. Mental attitudes, emotions, sense of self, autonomy and choice, independence, and community life participation are important to individuals with aphasia and their relatives (Hoen, Thelander, & Worsley, 1997; Le Dorze & Brassard, 1995; Zemva, 1999). Respondents reported substantially negative

consequences in these areas including altered communication, changes in communication situations, changes in interpersonal relationships, physical dependency, loss of autonomy, restricted activities, fewer social contacts, altered social life, and stigmatisation, and difficulty controlling emotions, as well as negative feelings such as loneliness, irritation, stress, anxiety, and annoyance (Le Dorze & Brassard, 1995; Zemva, 1999). These issues are not specific to the experience to aphasia. Adults with dysarthria and spasmodic dysphonia similarly report embarrassment, frustration, and lack of confidence, as well as changes in employment and social life (Baylor, Yorkston, & Eadie, 2005; Walshe, 2002).

The aforementioned studies did not expressly investigate psychological wellbeing, but rather interviewed respondents about the consequences of conditions and their experiences of life. We now turn our attention to the studies that have intentionally investigated psychological wellbeing, in incidentally, used quantitative measures to do so. Cruice and colleagues (2003) found a significant influence of language impairment on wellbeing in aphasia. Increasing language functioning and increasing functional communication ability significantly predicted increasingly positive psychological wellbeing in the dimensions of personal growth (being open to new experiences), positive relations with others (having satisfying high quality relationships), and self acceptance (a positive attitude towards oneself and one's past life) (Cruice et al., 2003).

Psychological wellbeing has also been studied as an outcome of speech and language therapy intervention, and evaluated using measures of anxiety, depression, self-esteem, psychological wellbeing, and qualitative interviews. Lyon et al (1997) reported insignificant findings for a standardized measure of affect, but significantly improved psychological wellbeing in their author-devised measure for participants in a communication partners' programme. Hoen et al (1997) found significantly increased psychological wellbeing in individuals and relatives

attending their aphasia centre programme. Van der Gaag and colleagues (2005) reported increased self-confidence and an increased desire to participate in individuals and relatives attending the groups at a charity organization for aphasia. Ross and colleagues (2006) found no evidence of group change in their seven participants' self esteem, although individual improvements were noted. Finally, Ross and Wertz (2003) compared a clinical and a normal population, and found significantly lower psychological wellbeing and quality of life in affected adults compared to non-brain-injured adults, in the domains of independence, environment, and social relationships. With the exception of this final study, it is not clear whether affected individuals have significantly reduced psychological wellbeing. Thus, this paper reports the psychological wellbeing of older adults with chronic aphasia comparing them to an unaffected similarly aged and educated normal population. The experience of completing the wellbeing measure with a language-impaired population is described, and the total wellbeing scores and dimension scores are compared between groups to determine whether aphasia does significantly reduce psychological wellbeing. It augments the findings of Ross and Wertz, with larger participant samples and by using a different measure.

Methodology

Participants

One hundred and five participants took part in this study - 30 with aphasia post-stroke (16 women, 14 men) and 75 without stroke and aphasia (47 women, 28 men). These two groups are referred to as affected and unaffected for ease of reading. Ethical approval for this study was gained from the relevant university and committees of three hospitals from which affected participants were recruited. Unaffected participants were recruited from a longitudinal research

study within the university department. These were a self-selected group who responded to advertising in community newsletters and newspapers, when the parent project began several years previously. New unaffected participants were recruited using snowballing sampling (i.e. members of the parent project were asked to introduce new members to the research).

Participants were 60 years or older, spoke English as their first language, and lived independently in the community, drawn from the same geographical area (metropolitan Brisbane and the surrounding area up to 150 kilometres). Two affected participants, aged 57 years and 59 years, were included as participants meeting the selection criteria were scarce. The affected group met the following criteria: had no concomitant neurological disease, confirmed by hospital file checks, clinical observation, and self-report at interview; were more than 10 months post-stroke; demonstrated aphasia at time of stroke and reported ongoing aphasic difficulties; had a reliable yes/no response (no less than 16/20 on *Western Aphasia Battery* (WAB) Yes/No Questions, Kertesz, 1982); had moderate comprehension ability at time of interviewing (no less than 5/10 on WAB Comprehension subtest); and had normal to moderate mobility (persons requiring a wheelchair were excluded). Unaffected participants were excluded if they reported a history of cerebrovascular or neurological disease.

Demographic information for both groups is presented in Table 1. Participants' occupations are reported in Appendix 1, as a crude indicator of socio-economic status. Judgment of participants' physical functioning has been made using the Physical Fitness Chart from the *Dartmouth COOP Charts* (Nelson et al., 1987), an assessment within the larger study (Cruice et al., 2003).

Participants reported the *hardest level of physical activity they could do for at least 2 minutes, during the last 4 weeks*. Five options are available and increasing numbers indicate poorer levels of physical fitness. Options are as follows: 1 = very heavy (run at fast pace, carry a heavy load

upstairs or uphill); 2 = heavy (jog at slow pace, climb stairs or hill at moderate pace), 3 = moderate (walk at a medium pace, carry a heavy load on level ground), 4 = light (walk at a medium pace, carry a light load on level ground), and 5 = very light (walk at a slow pace, wash dishes). Scores of 4 or 5 are considered abnormal functioning. Twenty-one affected participants (70%) reported abnormal scores, and similarly, 21 unaffected participants (28%) reported abnormal scores.

Information specific to affected participants in Table 2. Although the affected group had a range of language impairment (mild to moderate-severe) indicated by the WAB Aphasia Quotient scores, the majority of scores fell between 60 and 89, indicating a bias towards mild to moderate impairment. Four participants' scores exceeded the WAB AQ cut-off, yet had clear signs of aphasia, for example, not being able to formulate political speeches fluently anymore; not being able to study and speak a foreign language anymore. The researcher's clinical judgment (first author) regarding these participants' word finding and retrieval, thought and sentence formulation, and errors provided evidence of aphasic disruption to their language system. As functional communication skills are also predictive of psychological wellbeing (Cruice et al., 2003), average scores for affected participants on the *Communication Activities of Daily Living – Second Edition* (CADL-2: Holland et al., 1999) are reported.

Insert Tables 1 & 2 about here

Measures

The Ryff Psychological Well-being Scale (Ryff, 1989) measures six dimensions of psychological well-being: autonomy, environmental mastery, personal growth, positive relations with others,

purpose in life, and self-acceptance. A condensed version of the Ryff Short-Form was developed for people with aphasia at the York-Durham Aphasia Centre, Ontario (Thelander, Hoen, & Worsley, 1994) and was used in the current research. Containing 24 statements, this version was titled “*How I Feel About Myself*” and is referred to as the wellbeing measure (Appendix 2). The original measure is psychometrically sound, and the shorter version has been used successfully with people with aphasia and family members (Hoen et al., 1997) and there is adequate reliability and validity on five of the six new scales. The response scale generated for this research was ‘strongly disagree, disagree, some of both [or don’t know], agree, and strongly agree’. This was modified from the original six points to accord with typical formats for quality of life measures as well as personal reasons (the other quality of life measures used in a larger study by Cruice (2001) had five point response formats). Half of the statements are scored positively, and half negatively (items 2, 7, 10, 11, 14, 15, 16, 17, 18, 19, 21, 24), and numerical values from one to five were assigned to the response points. Thus, each subscale comprises four items (two positive and two negative). The latter are reversed in final scoring and thus higher scores indicate greater wellbeing. The possible range of overall scores is 24 to 120, while the possible range for subscale scores is four to 20. Subscales are comprised of the following items: autonomy (items 1, 7, 13, and 19); environmental mastery (items 2, 8, 14 and 20); personal growth (items 3, 9, 15, and 21); positive relations with others (items 4, 10, 16, and 22); purpose in life (items 5, 11, 17, and 23); and self-acceptance (items 6, 12, 18 and 24).

The 15-item version of the Geriatric Depression Scale (GDS: Sheikh & Yesavage, 1986) was used to measure depressive symptoms or emotional health, as past research indicated a significant influence of mood on reporting subjective information (Cruice et al., 2003). Participants answered ‘yes’ or ‘no’ to 15 questions depending on how they had felt over the past week.

Questions are counterbalanced, alternating positive and negative responses, and one point is counted for each depressive answer. A score of 0-4 indicates normal mood or emotional health status, 5-9 indicates mild depression, and 10-15 indicates moderate to severe depression. The GDS has good reliability, validity, sensitivity and specificity for older people (McDowell & Newell, 1996), and has been used in stroke (Jönsson, Lindgren, Hallström, Norrving, & Lindgren, 2005). Throughout the study, independent t-tests were used through the statistical analysis to compare data from affected and unaffected participants. Because the groups differ in size, Levene's test for homogeneity of variance was used in each comparison.

Procedure

The first author assessed each participant individually in his or her own home. The wellbeing measure is linguistically complex and thus challenging for language-impaired participants, and support was required during administration in the format of a cueing or prompting procedure. The first cue provided was an exact repetition of the item spoken more slowly and using chunked information. If necessary, a second cue was given as the item rephrased to reduce or simplify the item. If needed, a further third cue was provided and involved personalizing the item (based on previous shared knowledge between researcher and participant or the immediate physical and social environment). The cuing procedure has not been tested for reliability, although it was piloted, reviewed and discussed with international researchers in the same field (Cruice, Hirsch, Worrall, Holland, & Hickson, 2000). It is not known whether this affects the standardisation of the measure. Using systematic modifications however was preferable to excluding participants with aphasia and using family members as proxy respondents instead. The cues were originally instigated for affected participants' needs but were also used with unaffected participants who had difficulty understanding items. Items were often modified from statements to questions

(considered a rephrased cue), and the response format was subsequently altered from its agreement format to “NO!, no, ? or $\frac{1}{2}$ $\frac{1}{2}$, yes, YES!” with intonation and stress to emphasize the options.

Affected participants completed the wellbeing measure in an average of 21 minutes (SD = 8, range 7-47, N = 30) and unaffected participants in an average of 11 minutes (SD = 5.3, range 3-23, n = 55). Cues were recorded for some participants in both groups (Table 3). There was no significant difference between the subgroups of the unaffected participants (i.e. those with cues recorded versus those not recorded), whereas these aphasic participants (n=14) were significantly older than the others in their subgroup ($t = -2.5$, $p = .02$) but not significantly different in language abilities. Affected participants required significantly more cues during administration, and required significantly more of each type of cue than the unaffected participants (Table 4). To more closely examine wellbeing items, the cues that were given to the first eight consecutive affected participants were recorded for each item. Three items required no cueing (4, 17 & 22); and nine items required many cues, seven of which were negatively framed (2, 7, 15, 16, 18, 19, & 21), suggesting that grammatically complex statements need several stages of modification before they were comprehended.

Insert Tables 3 & 4 about here

Results

Compared to unaffected participants, affected participants were significantly younger (by 3 yrs; although this finding was non-significant when the two younger affected participants were removed from the comparison), had fewer years of schooling (formal schooling and further training; approximately 2.5 yrs), and had significantly higher GDS scores (by 2.5 points) indicating more depressive symptomatology or lower mood (Table 1). According to the cut-off scores of the GDS (see *Measures* above), 30% of affected participants (9 of 30) and 2.6% of unaffected participants (2 of 75) had scores indicating depressive symptoms or low mood. The average GDS score for unaffected participants in this study (mean = 1.17, SD = 1.13) is similar to a sample of 268 similarly aged New Zealand older adults (mean = 1.28, SD = 1.76; Knight et al., 2004). Seventy percent of affected participants reported abnormal functioning physical fitness, compared to 28% of their unaffected peers. They also had significantly lower physical fitness than unaffected peers (Table 1). Compared to health-related quality of life data on these same participant groups (Cruice, 2001), the wellbeing data demonstrated relatively more normal distributions of scores. In the affected group, the highest mean subscale score was for autonomy and the lowest was for environmental mastery, which also had the largest variability (Table 5). In the unaffected group, the highest mean subscale score was for environmental mastery, and the lowest was personal growth, which also had the largest variability (Table 5). In both groups, the mode rating of all items was equivalent to four on the response format or 'agree', indicating participants generally agreed with positive statements and disagreed with negative statements.

The means of total wellbeing and means of the subscales from both groups are similar (Table 5). Comparing the two groups statistically, affected participants had statistically similar wellbeing to unaffected participants in all areas (Table 5), with one exception of the environmental mastery subscale ($t = -2.93, .006$). The items of this subscale, which was significantly lower in the

affected group, are: *the demands of everyday life often get me down; I am quite good at managing the responsibilities of my daily life; I often feel overwhelmed by my responsibilities; and in general, I feel I am in charge of the situation in which I live.*

Insert Table 5 about here

For affected participants, better emotional health status correlated significantly and strongly with higher wellbeing (Total, environmental mastery, purpose in life, and self-acceptance) with correlations of -.6 and -.7 at $p = .005$ level. For unaffected participants, better emotional health status correlated significantly but weakly with higher wellbeing (Total, environmental mastery, positive relations with others, and purpose in life) with correlations of -.2 to -.4 at $p < .04$ level. Removing participants with defined depressive symptomatology (as per GDS cut-off: $n = 9$ affected and 2 unaffected participants) had little impact on the findings. Affected participants were still significantly younger, with fewer years of education, and with higher GDS average scores; and were not significantly different in any of the wellbeing comparisons.

Discussion

The first main finding of this research is that irrespective of group, wellbeing scores were reasonably normally distributed both in total wellbeing and in subscale wellbeing, and did not demonstrate skewness or floor and ceiling effects seen in health-related quality of life data (Cruice, 2001; Cruice et al., 2003). Thus, just as linguistic functioning and functional communication ability in aphasia is heterogeneous, so too is psychological wellbeing for individuals who were residing in the community and had been living with the effects of stroke for

an average of three and a half years. Further research is needed to explore whether evaluating wellbeing at an earlier time post onset reveals different findings, specifically whether range in wellbeing is more limited whilst individuals are still inpatients or within the first 12 months post stroke.

The second main finding is that older adults with and without aphasia are more similar in psychological wellbeing than they are different. Two explanations for this finding are proposed. Firstly, the measure used in this research may not have been sufficiently sensitive to discriminate between the clinical and normal population. The shortened and condensed version *How I feel about myself* may not have the same capabilities as its original standardized form, and may be less rigorous than the standardized tools used by Ross and Wertz (2003). Secondly, chronic aphasia may not significantly reduce the psychological wellbeing of affected individuals to a level lower than their premorbid status, as determined through comparison with the normal population, except in environmental mastery. Other studies (Nilsson et al., 2000) investigating quality of life post stroke in affected and unaffected groups also reported ‘non-significant’ findings. A non-significant difference challenges us to reflect on what we expect to find. Rather than comparing populations for difference, research may be better directed at investigating how individuals with and without aphasia live as “well” beings and what contributes to “ill” being in both groups. . Additional research is needed using different instruments to measure psychological wellbeing and in a more diverse participant sample. In this study, as in other studies (e.g. Nilsson et al., 2000), individuals with severe aphasia were excluded, introducing the risk that their views and needs will not be presented in the growing evidence base.

The third main finding of this paper was the significantly lower scores on the environmental mastery subscale (considered to reflect independence) for individuals with aphasia, which concurs with previous findings of lower or altered independence in adults with aphasia (Cruice, 2001; Le Dorze & Brassard, 1995; Ross & Wertz, 2003; Zemva, 1999) and other communication disorders (Baylor et al., 2005; Walshe, 2002). This finding suggests that specific attention to the demands and responsibilities of everyday life and people's emotional response to these is needed with all individuals with aphasia irrespective of the level of their linguistic impairment or ability to communicate functionally. Independence in the context of the wellbeing measure is not specifically linked to physical functioning, however individuals with aphasia demonstrated significant physical limitations. Further research, which is multidisciplinary in nature and involves evaluation of the person within the context of his environment, is needed to understand why and how independence is affected (whether it is due to physical ability, communication disability, social isolation, pre-existing health conditions, or combination of these etc) and to determine what can be manipulated or changed.

Thus, this study increases our understanding of psychological wellbeing for individuals with aphasia in the following ways: highlights the need to focus more on individuals' perceptions of the demands and responsibilities of their everyday lives; prompts us to consider the person's whole being (communication, physical, mood); and describes two measures that can be used in clinical evaluation with individuals with aphasia.

Clinical implications

In the speech and language therapy profession in the United Kingdom, there is a clear mandate to address psychological aspects in clinical management for both the individual and their family

(RCSLT Clinical Guidelines, 2005). This study suggests that intervention is needed in at least one area of psychological wellbeing and general mood for individuals with aphasia. One concern raised by this study is that the long time post onset means that many if not all of the affected individuals would not be likely to be receiving speech and language therapy or be in contact with the local service, and thus their needs would not be identified. A second concern is that although clinicians recognize the importance of psychosocial issues, they tend not to use formalized tools and assessments to identify and evaluate individuals in need, but prefer informal scales and communicative history forms (Brumfitt, 2006). Systematic identification of individuals in need requires formalized measurement, and this study indicates that formal measures of psychological wellbeing and mood are informative and viable with individuals with aphasia. The same measures may apply across different communication disorders (e.g. aphasia, dysarthria, dysphonia) and diseases (e.g. Parkinson's Disease, Multiple sclerosis) enabling identification and services to be more cost-effectively provided.

Healthcare and other service providers (e.g. leisure groups) situated within the community need to be aware that both affected *and* unaffected older adults accessing their services may have lower than average wellbeing, and thus that they have a potential role in identifying these individuals. Community screening with the wellbeing measure is unrealistic and inappropriate, however screening for factors that are predictive of lower wellbeing is possible. In aphasia, low mood is both predictive of psychological wellbeing (Cruice et al., 2003) and a concern in its own right, with 62% aphasic stroke patients depressed at 12 months post-stroke (Kauhanen et al., 2000). The *Geriatric Depression Scale* (originally designed for family physicians) is one such appropriate instrument for screening mood and can be used by the general practitioner (GP), providing that the person with aphasia has a reliable method of communicating yes and no, and

the GP has been trained in how to support the person's understanding and expression for the specific questions. Otherwise referral to the speech and language therapist and/or clinical psychologist is needed for screening. Actual diagnosis of depression in individuals with aphasia must be undertaken through collaboration of therapists and psychologists (Townend, Brady, & McLaughlan, 2007). The prevalence of low mood and wellbeing may be even greater than identified in this study, because of participation bias (i.e. participants with significantly affected wellbeing and mood did not volunteer). Identifying this subgroup is challenging, especially once they leave the formal healthcare system (i.e. discharged from speech and language therapy caseloads). Longitudinal research, starting in the early post-stroke stages, would be valuable in identifying determinants of later wellbeing. In normal ageing adults, there is no single strong predictor of low psychological wellbeing, making identification of this group more complicated and in need of further research.

The instrument *How I feel about myself* did require a high level of support for completion, however, individuals with aphasia engaged in the process and responded more positively to this measure than measures of health-related quality of life which were part of the larger study (Cruice et al., 2003). Anecdotally, items made more sense to participants and prompted spontaneous comments and discussion about their life situation (Cruice, 2001). Thus, the measure is clinically useful in speech and language therapy for measuring and discussing the psychological wellbeing of community dwelling individuals with mild to moderate chronic aphasia after stroke. This recommendation is in the context of those administering the measure being trained to identify and support the communication needs of the individual. This instrument has not yet been tested to determine whether it is appropriate for individuals with more moderate to severe aphasia, and relevant for patients in the hospital setting who are also at an earlier stage

in their recovery. The measure is not recommended for between group comparisons as it is unlikely to reveal significant differences. Other measures are available and require testing in clinical practice to determine suitability in adult neurology.

Conclusions

Adults with aphasia after stroke had similar psychological wellbeing as the unaffected population, with the exception of lower environmental mastery ,and also had lower mood. These findings suggest that *all* persons with aphasia may need support to manage the demands and responsibilities of their everyday lives, and some may need intervention to raise their mood. The further finding is that a substantial number of adults (affected and unaffected) reported lower than average psychological wellbeing. Whose role it is to address these issues - healthcare, social care, and/ or community services - requires further investigation. Multidisciplinary research using a range of measures and outcomes, targeting the environment as well as the individual, is needed to explore the causal factors of lower wellbeing as well as low mood and determine appropriate interventions.

References

Baylor, C., Yorkston, K., & Eadie, T. (2005). The consequences of spasmodic dysphonia on communication-related quality of life: A qualitative study of the insider's experiences. *Journal of Communication Disorders*, 38, 395-419.

Birren, J. E., Lubben, J. E., Cichowlas Rowe, J., & Deutchman, D. E. (1991). *The concept and measurement of quality of life in the frail elderly*. San Diego, CA: Academic Press, Inc.

Brumfitt, S. (2006). Psychosocial aspects of aphasia: Speech and language therapists' views on professional practice. *Disability & Rehabilitation*, 28(8), 523-534.

Cruice, M. (2001). *Communication and quality of life in older people with aphasia and healthy older people*. Unpublished PhD dissertation. Department of Speech Pathology and Audiology, University of Queensland, Brisbane, Australia.

Cruice, M., Hirsch, F., Worrall, L., Holland, A., & Hickson, L. (2000). Quality of life for people with aphasia: Performance on and usability of quality of life assessments. *Asia Pacific Journal of Speech, Language and Hearing*, 5, 85-91.

Cruice, M., Worrall, L., Hickson, L., & Murison, R. (2003). Finding a focus for quality of life with aphasia: Social and emotional health, and psychological well-being. *Aphasiology*, 17(4), 333-353.

Hoen, B., Thelander, M., & Worsley, J. (1997). Improvement in psychological well-being of people with aphasia and their families: Evaluation of a community-based programme. *Aphasiology*, 11(7), 681-691.

Holland, A., Frattali, C., & Fromm, D. (1999). *Communication Activities of Daily Living – Second Edition*. Texas: Pro-Ed.

Jönsson AC, Lindgren I, Hallström B, Norrving B, Lindgren A. (2005). Determinants of quality of life in stroke survivors and their informal caregivers. *Stroke*, 36(4), 803-8.

Kauhanen, M., Korpelainen, J., Hiltunen, P., Maatta, R., Mononen, H., Brusin, E., Sotaniemi, K., & Myllyla, V. (2000). Aphasia, depression, and non-verbal cognitive impairment in ischaemic stroke. *Cerebrovascular Diseases*, 10(6), 455-4461.

Kertesz, A. (1982). *The Western Aphasia Battery*. New York: Grune & Stratton.

Knight, R., McMahon, J., Green, T., Skeaff, M. (2004). Some normative and psychometric data for the Geriatric Depression Scale and the Cognitive Failures Questionnaire from a sample of healthy older persons. *New Zealand Journal of Psychology*, 33(3), 163-170.

Le Dorze, G., & Brassard, C. (1995). A description of the consequences of aphasia on aphasic persons and their relatives and friends based on the WHO model of chronic diseases. *Aphasiology*, 9(3), 239-255.

Lyon, J., Cariski, D., Keisler, L., Rosenbek, J., Levine, R., Kumpula, J., Ryff, C., Coyne, S., & Blanc, M. (1997). Communication partners: Enhancing participation in life and communication for adults with aphasia in natural settings. *Aphasiology*, 11(7), 693-708.

McDowell, I., & Newell, C. (1996). *Measuring health: A guide to rating scales and questionnaires*. (Second ed.). New York: Oxford University Press.

Nelson, E., Wasson, J., Kirk, J., Keller, A., Clark, D., Dietrich, A., Stewart, A., & Zubkoff, M. (1987). Assessment of function in routine clinical practice: Description of the COOP Chart method and preliminary findings. *Journal of Chronic Disease*, 40(1), 55S-63S.

Nilsson, A., Aniansson, A., & Grimby, G. (2000). Rehabilitation needs and disability in community living stroke survivors two years after stroke. *Topics in Stroke Rehabilitation*, 6(4), 30-47.

Royal College of Speech and Language Therapists (RCSLT). (2005). *RCSLT Clinical Guidelines*. London: RCSLT.

Ross, K., & Wertz, R. (2003). Quality of life with and without aphasia. *Aphasiology*, 17(4), 355-364.

Ross, A., Winslow, I., Marchant, P., & Brumfitt, S. (2006). Evaluation of communication, life participation and psychological well-being in chronic aphasia: The influence of group intervention. *Aphasiology*, 20(5), 427-448.

Ryff, C., (1989). Happiness is everything, or is it? Explorations on the meaning of well-being. *Journal of Personality and Social Psychology*, 57(6), 1069-1081.

Sheik, J. & Yesavage, J. (1986). Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. *Clinical Gerontology*, 5, 165-172.

Thelander, M., Hoen, B., & Worsley, J. (1994). *York-Durham Aphasia Centre: Report on the evaluation of effectiveness of a community program for aphasic adults*. Ontario: York-Durham Aphasia Centre.

Townend, E., Brady, M., & McLaughlan, K. (2007). A systematic evaluation of the adaptation of depression diagnostic methods for stroke survivors who have aphasia. *Stroke*, 38, 3076-3083.

Van der Gaag, A., Smith, L., Davis, S., Moss, B., Cornelius, V., Laing, S., and Mowles, C. (2005). Therapy and support services for people with long-term stroke and aphasia and their relatives: A six-month follow-up study. *Clinical Rehabilitation*, 19(4), 372-380.

Walshe, M. (2002). *"You have no idea. You have no idea what it is like...not to be able to talk"*. Exploring the impact and experience of acquired neurological dysarthria from the speaker's perspective. Unpublished doctoral thesis. Dublin: Trinity College.

Zemva, N. (1999). Aphasic patients and their families: Wishes and limits. *Aphasiology*, 13(3), 219-234.

Appendix 1

Occupations of affected and unaffected participants

One affected participant was unable to explain her occupation. The remaining 29 participants described their occupations as: housewife (2), harness maker, boilermaker, ferry boat driver, shoe sales assistant, receptionist/ clerk (4), book keeper, corner store owner, caravan park operator, betting agency worker, art worker, foreman/ supervisor, betting agency supervisor, radio station manager, bank manager, teacher (2), police officer, public servant, yachtsman, nursing assistant, radiographer, clinical pharmacologist, engineer, and marine engineer.

Unaffected participants described their occupations as: volunteer work; home duties (9); tailoress (4); weaver; milliner; secretary (5); clerk (2); seaman; boilermaker and inspector; shop assistant; bookshop; printer; newsagent; produce merchant; administration (5); officer (3 – liaison, technical, legal); public servant; teacher (7); university (3 – tutor, lecturer, reader); librarian (3); accountant (3); nurse (2); orthoptist; physiotherapist; anaesthetist; inspector/ supervisor (2); engineer (4); and manager (8 – including state industry, transport, disability organization, and company). Data is missing for one participant.

Appendix 2

“How I Feel About Myself”

Condensed Short-Form of Ryff’s Psychological Wellbeing Scale

as used by York-Durham Aphasia Centre

1. I have confidence in my own opinions, even if they are contrary to the general consensus.
2. The demands of everyday life often get me down.
3. In general, I feel that I continue to learn more about myself as time goes by.
4. Most people see me as loving and affectionate.
5. I have a sense of direction and purpose in life.
6. In general, I feel confident and positive about myself.
7. I tend to worry about what other people think of me.
8. I am quite good at managing the responsibilities of my daily life.
9. I am the kind of person who likes to give new things a try.
10. Maintaining close relationships has been difficult and frustrating for me.
11. My daily activities often seem trivial and unimportant to me.
12. I like most aspects of my personality.
13. Being happy with myself is more important to me than having others approve of me.
14. I often feel overwhelmed by my responsibilities.
15. I don’t want to try new ways of doing things - my life is fine the way it is.
16. I don’t have many people who want to listen when I need to talk.
17. I sometimes feel as if I’ve done all there is to do in life.

18. Given the opportunity, there are many things about myself that I would change.
19. I tend to be influenced by people with strong opinions.
20. In general, I feel I am in charge of the situation in which I live.
21. I gave up trying to make big improvements or changes in my life a long time ago.
22. I feel like I get a lot out of my friendships.
23. I find it satisfying to think about what I have accomplished in life.
24. Everyone has their weaknesses, but I seem to have more than my fair share.

Table 1. Demographic information for affected (N = 30) and unaffected participants (N = 75).

Variable	Mean		Standard deviation		Standard error of the mean		Range		Levene's test for equality of variance	t-test	Sig. (2 tailed)	Mean difference	Standard error of difference
	Affected	Unaffected	Affected	Unaffected	Affected	Unaffected	Affected	Unaffected					
Age	70.73	73.85	8.4	6.8	1.54	.79	57-88*	62-98	3.18, .08, equal	-1.98	.05	-3.12	1.58
Education	10.77	13.18	4.01	3.8	.73	.44	6-20	6-23	.09, .76, equal	-2.9	.005	-2.41	.83
GDS scores (0-15)	3.6	1.17	3.31	1.13	.6	.13	0-12	0-5	32.86, .000, sig. diff.	5.62	.000	2.43	.62
Physical functioning													

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* Two of the 30 affected participants were under 60 years of age (57 years and 59 years) but were included as participants meeting the selection criteria were scarce. Including these participants created the statistically significant difference between the groups, that is, with these two participants removed, $t = -1.4$, $p = .17$ (equal differences assumed; mean difference = -2.21, standard error of difference = 1.58).

** Education was calculated in terms of years spent in schooling, higher education and training.

*** Judgment of participants' physical functioning was made using the Physical Fitness Chart from the *Dartmouth COOP Charts* (Nelson et al., 1987). Five options are available (1-5), increasing numbers indicate poorer levels of physical fitness, and scores of 4 or 5 are considered *abnormal* functioning.

Table 2. Time post onset, language and functional communication scores in affected participants (N = 30).

Variable	Mean	Standard deviation	Minimum	Maximum
Time post onset (months)	41.1	25.6	10	108
WAB AQ (Max = 100)	74.34	18.56	21.9	95.8*
WAB SponSpee (Max = 20)	15.03	4.16	4	20
WAB Comp (Max = 10)	8.49	1.3	6.05	10
WAB Rep (Max = 10)	6.92	2.87	0	10
WAB Naming (Max = 10)	6.74	2.41	0	9.5
CADL-2 (Max = 100)	73.4	16.72	31	95

* Four participants exceeded standard 93.8 WAB cut-off but were included as they demonstrated clear aphasic impairment difficulties.

Table 3. Cues provided during administration of wellbeing measure to affected (n = 14) and unaffected (n = 38) participants.

Group	N	Repeated Mean, (SD), Range	Rephrased Mean, (SD), Range	Personalized Mean, (SD), Range	Total Mean, (SD), Range
Affected	14	4.7 (4.3) 0 – 14	6.5 (6.4) 0 – 19	1.6 (1.8) 0 – 5	12.9 (10.8) 0 – 37
Unaffected	38	0.8 (1.2) 0 – 5	1.1 (1.5) 0 – 7	0.1 (0.3) 0 – 1	2 (2.4) 0 – 12

Table 4. Cues provided to affected (n = 14) and unaffected (n = 38) participants during administration.

Variable	Mean		Standard deviation		Standard error of the mean		Range		Levene's test for equality of variance	t-test	Sig. (2 tailed)	Mean difference	Standard error of difference
	Affected	Unaffected	Affected	Unaffected	Affected	Unaffected	Affected	Unaffected					
Total number of cues	12.9	2	10.76	2.36	2.87	.38	0 – 37	0 – 12	29.12, .000, sig. diff.	3.75	.002	10.86	2.9
Repeated	4.71	.79	4.3	1.23	1.15	.2	0 – 14	0 – 5	29.89, .000, sig. diff.	3.36	.005	3.93	1.17
Rephrased	6.5	1.08	6.44	1.51	1.72	.25	0 – 19	0 – 7	29.35, .000, sig. diff.	3.12	.008	5.42	1.74
Personalized	1.64	.13	1.78	.34	.48	.06	0 – 5	0 – 1	68.5, .000, sig. diff.	3.15	.007	1.51	.479

Table 5. Total wellbeing and subscale scores for affected (N = 30) and unaffected (N = 75) participants.

Variable	Mean		Standard deviation		Standard error of the mean		Range		Levene's test for equality of variance	t-test	Sig. (2 tailed)	Mean difference	Standard error of difference
	Affected	Unaffected	Affected	Unaffected	Affected	Unaffected	Affected	Unaffected					
Total (max = 120)	88.1	90.4	11.47	6.71	2.09	.76	64-107	74-112	11.29, .001, sig. diff	-1.03	.31	-2.29	2.23
Autonomy (max = 20)	15.3	14.9	2.7	2.5	.49	.29	9-20	9-19	.35, .56, equal	.66	.51	.36	.55
Environmental Mastery	14.4	16.1	3.01	1.49	.55	.17	5-19	12-20	18.2, .000, sig. diff	-2.93	.006	-1.69	.58
Personal Growth	14.8	14.4	2.26	2.89	.41	.33	10-19	9-20	4.5, .04, sig. diff	.78	.45	.41	.53
Positive Relations with Others	14.5	14.6	2.22	2.08	.41	.24	11-19	9-20	.31, .58, equal	-.77	.44	-.35	.46
Purpose in Life	14.6	15.4	2.65	1.66	.48	.19	10-20	12-19	10.15, .002, sig. diff	-1.44	.16	-.75	.52
Self acceptance	14.6	14.8	2.73	1.71	.5	.2	9-20	8-18	12.82, .001, sig.	-.51	.61	-.27	.54

